

Hello I am Mary Corcoran and I'm 13 years old; my little brother Will has Cystic Fibrosis, unfortunately he wasn't diagnosed until three months after he was born. Cystic Fibrosis causes thick, sticky mucus that clogs lungs, which makes breathing difficult and it can result in fatal lung infections. The median life expectancy for someone with CF is 37 years. When my brother Willie was first born he was very fragile and was literally starving to death. Although, I barely remember this I know that it was very tough for my entire family to watch Will failing. It became routine to run Will to the doctors office everyday to weigh him. After not gaining an ounce for all that time my Mom, Bean Corcoran was determined to figure out what was wrong with Will, before we lost him.

Finally Will was diagnosed with CF, and it was quite a relief. Then he was enrolled in the state funded, Birth to Three program for failure to thrive. Newborn screening would have spared Will these milestone set backs. Now Will takes enzymes to digest food, and they have saved his life. At this point Will is older and he is a very good student, also he participates in after school activities like baseball. My sisters and I admire his fortitude.

You may not be aware that Cystic Fibrosis is screened in every hospital throughout the country except in Texas and Connecticut. When I was looking at the diseases that are being screened I saw that MSUD was on the list and it has a 1 in 468 thousand 996 chance of occurring of which there has been one confirmed case; whereas Cystic Fibrosis has a 1 in 3000 chance with 300 patients in Connecticut today. Why you would test for MSUD and not CF when it is much less frequently diagnosed surprises me! You also may not be aware that Cystic Fibrosis is one of the most common genetic diseases. This is information I would like you to absorb, because I love my brother, and I wish that his life didn't begin with a struggle to survive. Please change this law so that other families, in particular other Cystic Fibrosis patients don't begin life with this unknown burden.